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ABSTRACT

This qualitative study examines the perspectives of 14 teachers of students with severe disabilities whose role changed from special education teacher to integration facilitator. All 14 participants expressed strong beliefs that students with severe disabilities would learn more in an integrated environment. The teachers identified themselves as being part of general education, by identifying the school principal rather than the administrator of special education as their primary supervisor and support, by not wanting a special education label attached to their job title, and by identifying general education teachers as more helpful than special education colleagues. This is described as a process of cultural assimilation. Integration facilitators faced uncertainties about roles and responsibilities in their first year of work. This drove the integration facilitators to work with those in general education in a spirit of collaboration, but crossing the cultural boundary from special to general education required huge amounts of time and dedication. The integration facilitators needed to translate the language of special education so that general education teachers could understand them. All 14 experienced a lack of confidence in their new roles and found social support necessary during the initial weeks and months--support which often came from the other general education teachers. (Contains 29 references.) (JDD)

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Teachers of Students with Severe Disabilities: Experiencing Cultural Struggle in Inclusive Schools

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> No one formulated the problem as one requiring teachers to unlearn and learn - to give up highly overlearned ways of thinking at the same time they were required to learn new procedures and new ways of conceptualizing.
>
> S. Sarason, 1982

> To understand what possibilities lie ahead for special education, special educators must understand and more important, free themselves from that which has conditioned, limited, and institutionalized their professional thought and action.
>
> Skrtic, 1991

Change is a journey. This research is about the perspectives of teachers who educate students with severe disabilities. It discusses their thoughts on their changing roles in public schools. It was a qualitative study of these teachers' perspectives on their individual journeys of change. It described where they once taught and their beliefs then. The data included where and how they taught at the time of the study when they worked as integration facilitators.

These fourteen pioneering teachers had powerful things to tell me about their work, their students, their schools, and their hopes for society. I greatly appreciated their honesty and intensity in helping me answer the questions I had long been asking myself. Because their journeys have also been my journey, I am grateful for their voices.

Inclusion is a complex issue in the education of students with severe disabilities, affecting teachers, principals, administrators, students, families, and the entire school community. Inclusion is also an ongoing, controversial issue. It represents a continuing struggle by those on the *outside* who are attempting to *get into* the general education community and be full participants.

Besides students with severe disabilities, another group of people have also experienced exclusion from general education classrooms. Their exclusion has been

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extreme and isolating. This excluded group has been the special education teachers who educated students with severe disabilities. They were the marginalized (Stonequist, 1930) members of the teaching profession, spending their professional years outside of the general education culture. Through training and experience they have been socialized into special education, a culture of separateness.

As their job title changed from special education teacher to integration facilitator, so much more also changed that the metaphor of a journey seemed appropriate. Research questions were loosely organized around this metaphor. What were the teachers' perceptions about this journey of change? What had it been like for them to move from isolation to inclusion? How can their stories guide others who attempt to create school communities that value inclusion?

Defining the Students

The definition of a severe disability varies according to state regulations, school district resources, and medical interpretations. Traditionally the term "students with severe disabilities" described a range of students with physical, medical, mental, social, and emotional multiple disabilities. In this paper, the definition of The Association of Persons with Severe Handicaps (1986) was used: "Students with severe disabilities were defined as the intellectually lowest one percent of the school-age population or students with delays of three or more standard deviations in two or more areas of development." This one percent included learners who may have labels such as multiply handicapped, physically handicapped, deaf-blind, autistic, trainable mentally retarded, or moderately or profoundly retarded (Snell, 1993). Students with severe disabilities required extensive ongoing support in more than one major area (mobility, communication, self-care, learning) in order to participate in school and community. Less than ten percent of the nation's school-age special education population was considered severely disabled (Ysseldyke, Algozzine & Thurlow, 1992).

Integration Facilitators

Most teachers of students with severe disabilities who became integration facilitators had worked in a wide array of service delivery models. They had worked in the wards of state institutions, private institutions and schools, hospitals, basement classrooms, wings of schools, separate classrooms, and mainstream programs before entering general education classrooms.

Although the majority of students with severe disabilities were still educated in separate classrooms, integration facilitators were the small minority of teachers who educated students with severe disabilities in general education classrooms. Except for their own experiences as students, most teachers of students with severe disabilities never experienced the culture of general education.

Most integration facilitators received their training in special education when a model of segregated instruction existed. They were socialized into the community of special education and their expertise was in diagnosis, remediation, and behavior management. Many of them had never been in a general education environment as an educator nor had familiarity with general education curriculum and teaching methods.

The Movement toward Inclusion

This struggle for students with severe disabilities to be fully included in general education classrooms was sometimes called the movement toward inclusion. The inclusion movement incorporated the concepts of normalization (Wolfensberger, 1972) and least restrictive environment (P. L. 94-142). Inclusion is based on students with severe disabilities attending the same neighborhood/home schools as their brothers and sisters, and being placed in chronologically age-appropriate grades in natural proportion to the number of students with disabilities in the community. Inclusion also means that the necessary supports for an individualized education are provided within the general education classroom. Without supports a student is "dumped" and not "included." (Brown et. al., 1991).

Inclusion has come about through advocacy by families (Strully & Strully, 1985), visionary thinking by some administrators (Villa, Thousand, Stainback, & Stainback), research (Brown et al., 1989; Giangreco, Dennis, Cloninger, Edelman, & Schattman, 1993; Schnorr, 1990), and the courts. In the Rafael Oberti v. Board of Education of Clementon, New Jersey (1992) case, the judge ruled that a student labeled with mental retardation should be allowed to be educated full-time in the general education classroom and that "inclusion is a right, not a privilege for a set few."

However, in 1994 inclusion is not the norm. Many schools districts throughout Massachusetts and the country provide services to students with severe disabilities in the same segregated manner they did fifteen years ago.

In the Fourteenth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, the United States Department of Education (1992) reported that during the 1990-91 school year, 4,817,503 students (from birth through 21 years of age) received special education services. Thirty-one percent of those students received their education in separate classes or separate schools. Of students identified as having multiple disabilities, 74% were served in segregated environments. Obviously, the education of students with severe disabilities in general education classrooms is just beginning.

The Separation of Two Cultures

These few examples of the differences between general and special education are indicative of how separate the two cultures have been. Students with severe disabilities and their teachers only became part of public education in 1975. In the years that followed, the culture of special education was maintained and strengthened by the culture of general education; and so it developed, under conditions of isolation and segregation, a separate set of beliefs, traditions, rituals, and symbols.

Moreover, teachers of students with severe disabilities were socialized into a professional culture of separation. When they themselves were students in public school, that culture had been invisible. There was no apprenticeship of observation (Lortie, 1975) for those wanting to teach students with severe disabilities. The culture of general education had no need for a connection, especially to students with severe disabilities. Thus, although the two cultures often existed in the same school building, cultural boundaries were seldom crossed. Teachers existed in different worlds with no connection to one another. This situation was strengthened by feelings of ethnocentrism -- a belief that "nobody else can teach them" (Ferguson, 1987).

Table 1 Cultural Differences between General and Special Education

	General Education	Special Education
Traditions	Class size, 25-40 students	Class size, 6-12 students
	Age of attendance, 5-18	Age of attendance, 3-21
	Homogeneity is great!	Heterogeneity is great!
Beliefs	Some can learn.	All can learn.
	Teach to the middle.	Teach to the fringes.
Language	Scope and sequence	Goals and objectives
	Literacy	Communication
	Pre and post testing	Baselines and data
	Grade level	Mental age
	Specialists = art & music	Specialists = language therapy, occupational therapy, physical therapy
	Motivation	Cueing
	Work habits	Levels of assistance
	Process writing	Functional academics
Rituals	Report cards	IEP meetings
	Parent teacher meetings	Disability support groups
	Teacher conference	Home visits
	Graduation	Transition
Symbols	Workbooks and worksheets	Graphs on clipboards
	Stairways	Ramps, elevators, railings
	Long bus	Short bus
	Homework	Family notebook

SUMMARY AND DISCUSSION

"We're not in Kansas anymore, Toto," said Dorothy.
Baum, The Wizard of Oz

> It's quite an experience; it's been good and bad. As a human being I've grown from it because I've seen two cultures, two different ways of looking at life and death, the whole process of living. I've been able to pick out a philosophy of my own about certain things, and it's been good in that sense. But if I had to go through it again, I really don't know if I could have done it.
>
> Pasquilina, Italian immigrant
> (Namias, 1978, p. 169)

The fourteen integration facilitators in this study expressed a variety of thoughts on the journeys they had taken, from their previous roles as segregated teachers of students with severe disabilities to their present roles. All fourteen also indicated that the journey of defining their roles and clarifying their responsibilities was continuing.

Although their experiences differed, all of the participants were, to varying degrees, remarkably able to change and to value that experience of change. My original hunch at the beginning of the study had been that the intense pace and amount of change would swamp the beginning integration facilitators. I thought that the uncertainty of this new role for special education teachers would overwhelm not just the teachers, but the entire school community. It seemed likely that the increased work demands of collaboration, training others, supervising paraprofessionals in diverse locations, and modifying curricula would burn out those beginning in this new role. I predicted that integration itself and the movement towards inclusive schools would not survive because the actual implementors would not survive.

But, contrary to my assumptions, not one of the fourteen integration facilitators wanted to return to a segregated classroom. All believed that in their roles of integration facilitators they could make schools and society more inclusive. Although they had become integration facilitators for different reasons -- some by switching jobs, some by assignment, and some by seeking new positions -- they all expressed strong beliefs that students with severe disabilities would learn more in an integrated environment. The majority of teachers indicated that they and their students were thriving in the mainstream.

These teachers identified themselves as part of general education in many ways. First, nine integration facilitators identified the school principal, rather than the administrator of special education, as their primary supervisor and support. Second, the majority of participants expressed a dislike for the job title they were given, be it "integration facilitator" or "inclusion specialist," because they believed these titles interfered with their being accepted into general education. They wanted to be viewed as general education teachers who provided support to the entire school community -- to teachers, typical peers, parents, principals, and superintendents -- not just to a few students with severe disabilities. Rather than have a special education label attached to their job title, they wanted to be called "support teachers," a term that suggests their own desire to be included in the general education mainstream. Third, all fourteen integration facilitators identified at least one general education teacher in their building as more helpful than their special education colleagues. The general education teachers were identified as the primary resources for help with curriculum modification, adaptation of education materials, and the design of multi-level and parallel instructional activities. (It seemed that the integration facilitators were largely unsuccessful in explaining their roles and responsibilities to the special education teachers in their buildings. The latter continued to work in the special education culture and could neither identify with the work of the integration facilitators nor be supportive resources for them.)

These three indicators from my research showed that the integration facilitators experienced profound change in their work environment and their professional roles and responsibilities. I have interpreted this, along with the data, as evidence that they were experiencing a form of cultural assimilation.

Initially, all fourteen participants were firmly entrenched in the special education subculture of teaching students with severe disabilities. All had trained to become special education teachers, and twelve out of fourteen had sought graduate degrees in special education. All had Massachusetts certification in the areas of teaching students with

moderate or severe special needs, and all had been teachers in segregated special education classrooms; most had also worked in private special education schools. They were not beginning teachers: their years of special education teaching experience ranged from five years to twenty-five years. They had all taught students with severe, multiple disabilities. But after one or two years of working in the role of integration facilitator, they had abandoned their identification with the special education culture and instead identified themselves as part of general education.

I believe that they were able to assimilate themselves into the general education culture because they respected the new culture and realized they had much to learn. They reported having a personal vision of inclusion for their students and society that helped them when the traveling was tough. There were also a few "natives" (principals and general education teachers) to provide support, language translations, and explanations about the new culture. Once the integration facilitators decided that they couldn't go back, they knew they had to make it work where they were. They made it work by letting go of much of special education, by giving up ownership of students, and blending themselves into general education. They slowly adjusted to the beliefs, traditions, language, symbols, and rituals of general education.

Skrtic (1991) would also have argued that they shifted more than the cultures of general and special education. He would have said they became less specialized and more generalized. Maria described this type of shift:

> I think in special education we're so used to saying: "This kid needs this, that kid needs that." What you really find out is, depending on what's going on in the classroom and with the teaching staff, that if you just change a little bit, the students are going to still come out ahead. And that is because of integration. Each room is very different in how we, as facilitators, are used. We still haven't figured out one traditional role for everybody. Some of the people here will walk out of a fifth grade classroom and walk into a second grade classroom and do something completely different. It all ends up being pretty successful. It sounds crazy, but it works.

The Challenge of Assimilation

The integration facilitators interviewed for this study all described the difficulties faced in their first year of work. The uncertainties about roles and responsibilities were never-ending. Most worked without a job description, but were encouraged to develop their own. One question that this opened up was whether they were functioning as support persons for students with severe disabilities or were instead supporting all students because of their assimilation into general education. Diana, a middle school "support" teacher said:

> I coteach social studies with a wonderful man here who sort of got into this warily and has become completely sold on how exciting it is. We spend an enormous amount of time planning together, but he really feels this planning has enhanced his teaching with all of his kids. He doesn't think of "those integrated students" as my students and the rest of them are his students. We share the phone calls home. We sign progress reports together. I mean, everything is done together for all the kids in our class. And that's the model I want to see.

Crossing cultural boundaries and getting to know the "natives" required huge amounts of time and dedication. Learning to be bilingual required studying and reading about general education culture. The work of educating students with severe disabilities had once seemed so certain, so clear in the segregated classroom. Now all these familiar strategies were questioned. The traditions of special education were being challenged, as students and teachers together journeyed to a new place with a different culture.

Identity. During this journey teachers began to lose their identity, their professional label. At the same time, they were no longer thought of by their peers as marginalized; they were living in the mainstream. Joe, a participant who had spent eight out of ten years in segregated classrooms, said:

> I like inclusion. I like that I get to work in the classroom. I'm not isolated and I know now how the kids must have felt because I felt very isolated. My personality is such that I don't want to be an isolated teacher. I feel like I'm more in the mainstream of what I'm teaching and what I'm doing if I'm with regular teachers and regular kids.

They were uncertain about their new identity, and even in the literature, their job title was inconsistent. They themselves wanted to be called support teachers, to have no identifiers

in their title related to special education. They wanted to be identified with the general education culture.

Translation. The integration facilitators needed to be "bilingual" and translate the language of special education (Individualized Education Plans, quarterly progress notes, toileting charts, etc.) for use in a new environment, so that general education teachers could understand them. In order to do this, the integration facilitators had to learn the language of general education; they had to read the literature of teaching students without disabilities. By reading the general education literature, they learned that the raging debates in education reform were not about the use of facilitated communication (Biklen, 1990) or object boards versus sign language. Whole language versus phonics was the current controversy spoken about in the teachers' lunchroom. There were new issues, new concerns, new challenges.

New dilemmas. Great confusion existed about the new culture. How would their students be graded? Would they receive report cards? If the students no longer used the back entrance of the school when they arrived by bus, did that mean they arrived at the same time with the rest of the school? If they arrived with the rest of the school, did they still need to take separate transportation? If they used long busses did they still need assistance on the bus? Was that assistance provided by a paid paraprofessional or a peer buddy? How did you plan class field trips for someone in an electric wheelchair? Did the student with severe disabilities follow the class bus in a private wheelchair van, or did the student with severe disabilities not go on the trip? What if the dilemma was solved by suggestions from the general education teachers? Did that reduce the professional specialization of the integration facilitator? What if the integration facilitators were so confused in the new culture, they could not be supportive to the general education community?

The integration facilitators spoke of seeing the great tragedies of general education first hand (Kozol, 1991), where there were no entitlements and federal laws to dictate educational resources. They saw the inequities in resource allocation and the lack of a

personalized (Sizer, 1992) education experience. They realized that not everyone had the legal benefits of an Individualized Education Plan. Every day spent in the general education culture created more questions, more dilemmas, more confusion. The integration facilitators initially experienced daily high dosages of cultural shock, sometimes paralyzing, sometimes invigorating, but always present.

Working together. Each of the integration facilitators reported the challenges and joys of working with others during the initial months of upheaval. All fourteen reported that they experienced a lack of confidence in their new roles and that they found social support necessary during the initial weeks and months. This support often came from their new peers, other general education teachers, who were having their own feelings of inadequacy at how to help the students with severe disabilities fit in (Giangreco, Dennis, Cloninger, Edelman, & Schattman, 1993). This finding was interesting, because it indicated that lack of confidence and certainty was both a demon and a savior to the participants: it created a need to cross over cultural borders and bureaucratic structures.

Confusion and chaos can create defensiveness and isolation, or it can nourish true mutual collaboration. In this case, uncertainty drove the integration facilitators to work with those in general education in a spirit of collaboration. (Possibly their background in working with a broad array of specialists in the field of severe disabilities, helped them apply these collaborative skills in this situation.) To get the help they needed, they let go of the outside consultant role and began to learn about teaching in the general education culture.

By shifting to the culture of general education, the integration facilitators were no longer the experts imposing special education knowledge from above. Each became a team player trying to sort out the challenges of integrating a student with severe disabilities into the social, physical, and academic world of general education.

When integration facilitators were placed in the middle of the general education culture rather than above it, problem solving required that they be sensitive to the concerns of general education teachers. Katie said:

> The teachers in this school are always worried about the curriculum demands and what kids are supposed to learn in a year. I understand that now. I understand that I have to spend a lot of time helping teachers relax and realize modifications are OK. I have to help with the fact that Johnny only has three math columns on his page, but last year he did zero and now he's making progress.

This type of realization was typical of these fourteen teachers during their first years as integration facilitators. They indicated an understanding that it was not enough to simply bring special education to general education: meeting halfway did not bring success. In order to have successful collaboration, this mutual respect needed to develop.

These teachers believed that the greatest disability was seeing the pathology before seeing the person. Sandra shared her thoughts about students with learning problems:

> I am of the opinion there are no child failures, there are only teacher failures. But you see, that's from my own perspective; I have no magic, as you know. If you've been a special education teacher, they always assume that they can give any kid to you. All you do is take the kid where you find him and identify some strengths and weaknesses and capitalize on what he knows. And everybody knows something. Every kid does know something that you can build on. But I suppose I wouldn't have known that, if I hadn't come from a background of teaching very severe kids.

The fourteen teachers in this study did not want these beliefs and values to be lost as they became assimilated into the new culture. They wanted these values to be adopted and to become part of the general education culture, as general education assimilated these ideas. They hoped that positive pieces of general education could be blended with some of the basic values they treasured from special education. This was their hope for school and society.

Leaving others behind. Change was and is difficult; uncertainty can paralyze or energize. But the integration facilitators wanted to convince others that it was worth the journey. They wanted to let their colleagues know that assimilation was possible, to convince others that the special education culture could be blended into the culture of general education.

Working as integration facilitators created the opportunity for these teachers to renew the idealism that led them to special education careers long ago. Their commitment to serve students with severe disabilities was deeply ingrained. But many integration facilitators described their work as having become isolating and routine over the years. Integration was the rebirth of the initial idealism that had originally led them to special education. They also were renewed by working with typical students and sharing their values with them.

They began to wonder if they could convince colleagues in special education to make the journey they had made. Kim felt she still had a lot of work to do with her special education colleagues:

> They say, "Oh, Kim, you are living in Never Never Land,", kiddingly, of course. But there are districts, there are places, that do not have special education. You know what I mean? They don't have it. That's a goal I want to help people work toward. So they can realize education is education is education.

Table 2

About the Teachers

	Highest Degree	Certification	Years as Teacher	Years as Integration Facilitator	Reason for Taking Position
Ben	M.Ed.	Severe	13	6	Volunteer
Betty	M.A.	Moderate 1993	5-aide	2	New position
Charlotte	M.Ed.	Moderate, Elementary	17	2	Volunteer
Diana	Ed.D.	English, Mod, SPED Admin..	14	2	New position
Didi	M.Ed.	Sev. Speech, Elem. Mod.	10	1	New position
Dolores	B.S.	Moderate, Elementary	8	5	Volunteer
Joe	M.Ed.	Moderate, Elementary	10	1	Volunteer
Katie	M.Ed.	Moderate, Elementary	5	2	Volunteer
Katrina	M.Ed.	Elem, Mod., Sped Admin. Principal	20	1	New position
Kim	B.S.	Severe	8	2	Volunteer
Maria	M.Ed.	Generic SPED, Mod	21	3	Volunteer
Rita	M.Ed.	Generic SPED Elem	15	2	Required
Sally	M.Ed.	Severe, Moderate, Elementary	12	1	New position
Sandra	M.A.	Mod, Severe, Elem, Art	25	2	Required

Table 3 About the Schools

	Kind of Community	School Size	Grades	Number of Students	% of time in General Education	Number of Aides	Direct Supervisor
Ben	U	545	K-8	6	80%	6	SPED Admin.
Betty	R	860	1	3	90%	3	Principal
Charlotte	S	139	K - 2	7	66%	4	Principal
Diana	S	610	6-8	7	50%	1	Asst. Princ.
Didi	S	4 schools	K - 1	4	80%	4	SPED Admin.
Dolores	R	103	K - 6	8	90%	1	SPED Admin.
Joe	U	327	4,5,6	15	100%	2	Principal
Katie	S	560	K - 5	14	75%	1	Principal
Katrina	S	400	K-2	7	90%	5	Principal
Kim	R	4 schools	K-6	15	90%	15	SPED Admin.
Maria	R	280	K - 5	25	98%	5	Principal/SPED Admin.
Rita	S	320	K - 3	6	70%	13	Principal
Sally	S	470	6-8	1	50%	1	Principal/SPED Admin.
Sandra	S	468	K - 3	28	80%	7	Principal

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